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# Online support groups for women with breast cancer (Review)

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Online support groups for women with breast cancer.
*Cochrane Database of Systematic Reviews* 2017, Issue 3. Art. No.: CD011652.
DOI: 10.1002/14651858.CD011652.pub2.

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[Intervention Review]

# Online support groups for women with breast cancer

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**Editorial group:** Cochrane Breast Cancer Group.
**Publication status and date:** New, published in Issue 3, 2017.

**Citation:** McCaughan E, Parahoo K, Hueter I, Northouse L, Bradbury I. Online support groups for women with breast cancer. *Cochrane Database of Systematic Reviews* 2017, Issue 3. Art. No.: CD011652. DOI: 10.1002/14651858.CD011652.pub2.



## ABSTRACT

### Background

Survival rates for women with a diagnosis of breast cancer continue to improve. However, some women may experience physical, psychological and emotional effects post diagnosis, throughout treatment and beyond. Support groups can provide opportunities for people to share their experiences and learn from others. As the number of online support groups increases, more and more women with breast cancer will likely access them.

### Objectives

To assess effects of online support groups on the emotional distress, uncertainty, anxiety, depression and quality of life (QoL) of women with breast cancer.

### Search methods

We searched for trials in the Cochrane Breast Cancer Specialised Register, the Cochrane Central Register of Controlled Trials (CENTRAL; 2016, Issue 4), MEDLINE, Embase and PsycINFO on 2 May 2016, and we handsearched journals and reference lists. We also searched the World Health Organization's International Clinical Trials Registry Platform (WHO ICTRP) search portal and clinicaltrials.gov on 2 May 2016.

### Selection criteria

We included randomised controlled trials (RCTs) assessing effects of online support groups on women with a diagnosis of breast cancer and women who have completed breast cancer treatment. We included studies comparing online support groups with a usual care group, and studies comparing two or more types of online support groups (without a usual care group).

### Data collection and analysis

Two review authors independently extracted data and assessed risk of bias. We presented outcome data using mean differences (MDs) and standardised mean differences (SMDs) along with 95% confidence intervals (CIs), and we used the fixed-effect model when appropriate. We assessed the quality of the body of evidence using the GRADE approach.

### Main results

We included six studies (492 women) that assessed online support groups for women with breast cancer. Online support groups in these six trials lasted from six to 30 weeks. Women participated in these groups between 1.5 and 2.5 hours per week, and investigators conducted all studies in the USA. Participants were predominantly white and well educated and were moderate to high earners. Four studies compared an online support group versus a control group, and the other two compared a 'moderated' versus a 'peer-led' online support group, and a 'standard' versus an 'enhanced' online support group, respectively.

None of the included studies measured 'emotional distress' or uncertainty. One study (78 women) for which data for analysis were missing reported no positive effects of online support on 'distress' and 'cancer-specific distress' versus support provided by a control group. Two studies measured anxiety: One study (72 women) found no difference in anxiety at the end of the intervention between the online support group and the control group (MD -0.40, 95% CI -6.42 to 5.62; low-quality evidence), and the second study (184 women) reported a reduction in anxiety levels at the end of the intervention when comparing the 'standard' support group (run by participants without prompting from health professionals) versus an 'enhanced' online support group (in which participants were specifically asked by the researcher to respond to one another's need for support).

Five studies (414 women) measured depression. Three studies compared depression in the online support group with depression in the control group. Pooled data from two studies (120 women) showed a small to moderate reduction in depression in the online support group compared with control groups at the end of the intervention (SMD -0.37, 95% CI -0.75 to 0.00; very low-quality evidence). The third study, a pilot study (30 women), provided no data for analysis but reported no difference in depression between participants in support and control groups at the end of the intervention. Of the remaining two studies that measured depression, one study (60 women) provided no extractable data for comparison but reported no difference in depressive symptoms between a 'moderated' and a 'peer-led' support group; the other study (184 women) reported greater reduction in depression in the 'standard' support group than in the 'enhanced' online support group.

Three studies measured quality of life. One pilot study (30 women) provided limited data for analysis but reported no change in quality of life at the end of the intervention. Only two studies (140 women) provided data for pooling and showed no positive effects on quality of life at four months post intervention compared with controls (SMD -0.11, 95% CI -0.47 to 0.24; very low-quality evidence). At 12 months post intervention, one study (78 women) reported that the intervention group did not attain better quality of life scores than the control group (MD -10.89, 95% CI -20.41 to -1.37; low-quality evidence).

We found no data for subgroup analyses on stage of disease, treatment modality and types and doses of interventions. No studies measured adverse effects.

### Authors' conclusions

This review did not find the evidence required to show whether participation in online support groups was beneficial for women with breast cancer, because identified trials were small and of low or very low quality. Large, rigorous trials with ethnically and economically diverse participants are needed to provide robust evidence regarding the psychosocial outcomes selected for this review.

## PLAIN LANGUAGE SUMMARY

### Online support groups for women with breast cancer

### Review question

We reviewed the evidence for effects of online support groups for women with breast cancer on emotional distress, uncertainty, anxiety, depression and quality of life.

### Background

Women with a diagnosis of breast cancer can be affected physically, psychologically and emotionally. They are uncertain about the future and may need information and support to help them cope with their condition. Increasingly, people with cancer are accessing the Internet to seek the information and support that they need; many join online support groups. At this time, we know little about how participation in online support groups psychologically and emotionally affects women with breast cancer.

### Study characteristics

We conducted a systematic search of the literature with no restrictions on language or country. We included in this review six studies, with a total population of 492 women with breast cancer. Five of the six studies had small samples. Study participants were predominantly 'white', well-educated women with moderate to high income at any stage of breast cancer who were undergoing a range of treatments.

Online support groups in these six trials lasted six to 30 weeks and included eight to 15 members. Women participated in these groups between 1.5 and 2.5 hours per week. Investigators reported all trials in English and conducted their research in the USA.

### Key results

None of the included trials measured emotional distress or uncertainty. Women who participated in online support groups showed no improvement in anxiety or quality of life when compared with those in control groups (which included women with similar characteristics who did not participate in online support groups). However, women who took part in online support groups showed a small to moderate reduction in depression when compared with those in control groups.

Results revealed no difference in depression between groups led by peers and those led by health professionals. However, women taking part in standard online groups (run by participants without prompting from health professionals) reported a greater reduction in depression and anxiety than those in other types of online groups (in which women were asked specifically by the health professional to respond to one another's need for support).

**Quality of the evidence**

Small studies of low or very low quality attributed mainly to poor study design and other shortcomings have provided evidence on the effectiveness of online support groups for women with breast cancer. Large, rigorous trials including ethnically and economically diverse participants are needed to provide robust evidence on the effectiveness of online support groups for women with breast cancer.

## SUMMARY OF FINDINGS

### Summary of findings for the main comparison. Online support group for women with breast cancer

**Online support group for women with breast cancer**

**Patient or population:** women with breast cancer
**Setting:** hospital and community
**Intervention:** online support group
**Comparison:** usual care

| Outcomes | Relative effects* (95% CI) | Number of participants (studies) | Quality of the evidence (GRADE) | Comments |
|---|---|---|---|---|
| | Online support group vs usual care | | | |
| Emotional distress | Not reported | | - | Emotional distress was not measured. However, 1 study reported that the intervention did not have a positive effect on "distress" and "cancer-specific distress" |
| Uncertainty | Not reported | - | - | None of the 6 included studies measured this outcome |
| Anxiety at end of intervention<br><br>Assessed with STAI<br><br>at 1 time point (end of a 12-week intervention) | Mean anxiety in the intervention group was **0.4 lower at end of intervention** (95% CI 6.42 lower to 5.62 higher) | 58<br>(1 RCT) | ⊕⊕⊖⊖<br>Low[a,b] | |
| Depression at end of intervention<br><br>Assessed with CESD (both studies measured depression at 1 time point (end of intervention) | Mean depression in the intervention group was **0.37 standard deviations undefined lower** (95% CI 0.75 lower to 0) | 120<br>(2 RCTs) | ⊕⊖⊖⊖<br>Very low[b,c,d,e] | |
| Quality of life post intervention<br><br>Assessed with FACT-B at end of intervention | Mean quality of life (at end of intervention) in the intervention group was **0.11 standard deviations undefined lower** (95% CI 0.47 lower to 0.24 higher) | 140<br>(2 RCTs) | ⊕⊖⊖⊖<br>Very low[b,c,d,f] | |
| Quality of life 12 months post intervention<br><br>Assessed with FACT-B | Mean quality of life in the intervention group (at 12 months post intervention) was **10.89 undefined lower** (95% CI 20.41 lower to 1.37 lower) | 78<br>(1 RCT) | ⊕⊕⊖⊖<br>Low[a,b] | |

*__Risk in the intervention group__ (and its 95% confidence interval) is based on assumed risk in the comparison group and the __relative effect__ of the intervention (and its 95% CI)
CI: confidence interval; OR: odds ratio; RR: risk ratio

**GRADE Working Group grades of evidence**
**High quality:** We are very confident that the true effect lies close to the estimate of effect
**Moderate quality:** We are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of effect but may be substantially different
**Low quality:** Our confidence in the effect estimate is limited: The true effect may be substantially different from the estimate of effect
**Very low quality:** We have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of effect

[a]Lack of information on randomisation, concealment and blinding of participants and personnel
[b]Small sample
[c]Randomisation may have been compromised in one study
[d]Lack of information on concealment and blinding of participants and personnel
[e]Different populations
[f]High statistical heterogeneity

# BACKGROUND

## Description of the condition

Breast cancer is the most common cancer among women, with an estimated 1.67 million new cancer cases diagnosed in 2012 worldwide (Ferlay 2012). Breast cancer incidence rates vary according to country, age, gender and socioeconomic group. In the USA alone, it was estimated that there will be more than 255,180 new cases of breast cancer among women in 2017 (American Cancer Society 2017). With early detection and advances in medical diagnostics and treatment, the number of people surviving cancer, in general, has increased significantly since the mid-1990s. Five-, 10- and 15-year relative survival rates for women with a diagnosis of localised breast cancer in the USA were 89%, 83% and 78% in 2015, and death rates among women, especially younger women, have decreased steadily since 1989 (American Cancer Society 2017). Worldwide, there were 6.3 million women alive who had been diagnosed with breast cancer in the previous five years (International Agency for Research on Cancer 2013). The UK reported 1.6 million breast cancer survivors in 2010, and it is expected that this figure will grow at a rate of over 3% each year (Department of Health 2010).

Although survival rates have improved, women with breast cancer may experience many physical and psychosocial problems following diagnosis and during and after treatment, including fatigue, anxiety, depression, effects on body image, loss of employment, adverse effects of treatment and breakdown in relationships (Department of Health 2010). These events can impact a woman's quality of life (QoL). One review of 477 studies on the QoL of people with breast cancer reported that psychological factors predicted subsequent QoL or even overall survival (Montazeri 2008). In particular, breast cancer survivors 50 years of age or younger experience greater reduction in QoL than older survivors, along with distinct psychosocial and menopause-related concerns, weight gain and physical inactivity (Howard-Anderson 2012).

## Description of the intervention

Support groups are a popular resource for people looking for information and support from peers to help them cope with their condition. In 2005, it was estimated that more than 400,000 Internet cancer support groups were available (Im 2005). The Internet will increasingly be the arena of choice for patients seeking psychosocial help in the future, not least because it can be accessed with relative ease by millions of people across wide geographical areas, from the comfort of their own homes. No consensus has been reached on the definition of support groups (Cancer Council Australia 2005), but they can be described as a form of peer support that consists of group members meeting face-to-face or communicating by telephone or via the Internet (including email and Facebook) for the purpose of sharing information and experiences and providing support on an issue or on topics of mutual interest.

Support groups vary in terms of membership, structure, leadership, delivery and setting. Some support groups are open to people with all types of cancer, and others are specific to one type of cancer. Some support groups are set up and led by health professionals as a psychosocial intervention (often based on cognitive-behavioural theories) with clear outcomes (e.g. see Lepore 2011). This type of support group has a defined therapeutic intent. In contrast, support groups can be loosely structured, informal and flexible enough for group members to take part when they feel the need to do so and to discuss any relevant issue they want. These groups may be facilitated or 'serviced' by the people who set them up. Their main function is to provide a forum for group members to share information and experiences. Such groups have a 'supportive' intent. In reality, both types of groups may have therapeutic and supportive elements, and many groups may fall between these two types.

## How the intervention might work

Support groups are based on the principle of self-management, by which individuals take responsibility and become proactive in seeking ways to address their problems. For support groups, the underlying belief is that collectively, the group has a pool of knowledge and experiences that can benefit individuals who become members of these groups.

A cancer diagnosis and subsequent treatment can be perceived as overwhelming, especially if the person with cancer does not have the resources to cope. Support groups provide opportunities for people with cancer to compare experiences and learn about different ways that other people experience and cope with cancer. Social comparison is premised on the concept that humans have a need to look externally for images and information as they evaluate their own opinions and abilities (Festinger 1954).

Investigators have used the social cognitive theory (Bandura 1997) and the transactional theory of stress and coping (Lazarus 1984) as frameworks to explain the process of coping with a stressful event such as breast cancer. Information plays a crucial role in social cognitive theory, in that it enables individuals to cognitively frame and reframe their perceptions of the challenges they face during their cancer journey. The transactional theory of stress and coping posits that when people are faced with a threat, they appraise it in terms of how challenging or controllable it is. They also appraise their own and external resources at their disposal to help them face the threat; how they eventually cope depends on these appraisals (Parahoo 2013). The ability to appraise and cope with problems and difficulties engenders a sense of control and empowerment (van Uden-Kraan 2008). Support groups can also reduce social isolation and loneliness (van Uden-Kraan 2008).

## Why it is important to do this review

There is little evidence about 'what works for whom' to inform the development of support groups for people with cancer, and for those in specific subgroups of cancer who may have different needs (Cancer Council Australia 2005). With increasing availability and access and improved skill in using online resources, it is likely that online support groups will increasingly play a key role in providing support for women with cancer. To date, no systematic review has examined the effectiveness of online support groups for women with breast cancer. Review authors must assess the state of research on this topic to make recommendations for future policy, practice and research.

# OBJECTIVES

To assess effects of online support groups on the emotional distress, uncertainty, anxiety, depression and QoL of women with breast cancer.

# METHODS

## Criteria for considering studies for this review

### Types of studies

All randomised controlled trials (RCTs) assessing effects of online support groups on women with a diagnosis of breast cancer and those who have completed treatment for breast cancer. We included studies comparing online support groups with a usual care group, and studies comparing two or more types of online support groups (without a usual care group). We applied no language restrictions.

### Types of participants

Included studies enrolled women with a diagnosis of breast cancer (any stage), disease free or not. Studies with mixed cancer populations and studies including partners were eligible for inclusion if they provided separate data for women with breast cancer. We included all types of treatment and applied no restrictions regarding age, ethnicity or setting.

### Types of interventions

All types of support groups involving more than two participants, offered via the Internet in the form of messaging (on a dedicated website or through email) or chat rooms, were eligible. We included both professional and user-led groups and combinations of these types of support. We excluded studies that evaluated a combination of face-to-face, telephone and online communication. We imposed no restrictions related to dose, frequency, intensity or duration of the intervention.

We compared online support groups against an inactive control intervention group (standard care or waitlist control) or against an active control intervention group (e.g. another form of psychological intervention).

### Types of outcome measures

#### *Primary outcomes*

- Emotional distress: assessed by validated instruments such as the Brief Symptom Inventory-18 (BSI-18) or the Profile of Mood States (POMS)
- Uncertainty: assessed by a validated instrument such as the 28-item Mishel Uncertainty in Illness Scale
- Anxiety: assessed by validated instruments such as the State-Trait Anxiety Inventory (STAI), the Beck Anxiety Inventory (BAI) and the Hospital Anxiety and Depression Scale-Anxiety (HADS-A)
- Depression: assessed by validated instruments such as the Beck Depression Inventory (BDI, BDI-II) and the Center for Epidemiologic Studies Depression Scale-Revised (CESD-R)

#### *Secondary outcomes*

- QoL: assessed by validated instruments such as Medical Outcomes Study 36-item Short Form (MOS SF-36), the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire-Core 36 (QLQ-C30) and the Breast Cancer-Specific Quality of Life Questionnaire (QLQ-BR23)

## Search methods for identification of studies

### Electronic searches

We searched the following databases on 2 May 2016.

- Cochrane Breast Cancer Specialised Register. Details of search strategies used by the Cochrane Breast Cancer Group (CBCG) for identification of studies and procedures used to code references are outlined in the CBCG module (onlinelibrary.wiley.com/o/cochrane/clabout/articles/BREASTCA/frame.html). We extracted trials with the key words "breast cancer", "support group", "online", "on-line", "internet", "web-based", "email", "chat room", "bulletin board", "computer" and "social network" and considered them for inclusion in the review.
- Cochrane Central Register of Controlled Trials (CENTRAL; 2016, Issue 4). See Appendix 1.
- MEDLINE (via OvidSP; from 2008 to 2 May 2016). See Appendix 2.
- Embase via Embase.com (from 2008 to 2 May 2016) and Embase via OvidSP (from 2015 to present). See Appendix 3.
- PsycINFO (via OvidSP; 2 May 2016). See Appendix 4.
- World Health Organization (WHO) International Clinical Trials Registry Platform (ICTRP) search portal for all prospectively registered and ongoing trials (apps.who.int/trialsearch/Default.aspx). See Appendix 5.
- ClinicalTrials.gov (clinicaltrials.gov/). See Appendix 6

### Searching other resources

#### *Bibliographic searching*

We searched the reference lists of identified relevant trials and reviews. We obtained a copy of the full-text article for each reference reporting a potentially eligible study, but we found no new studies.

We searched the Internet for reports and other literature related to the objectives of this review, but we identified no additional studies, other than those obtained from the databases listed above.

## Data collection and analysis

### Selection of studies

In the first stage of selection, we assigned all studies (after removal of duplicates) an identification number. Two review authors (EM and KP) independently read all abstracts to decide whether we should include, exclude or wait for full versions of the papers. We contacted a third review author (LN) when we encountered discordance in the first pair's decision, or when we needed further advice. At the second stage, we obtained full versions of all selected papers, and two review authors (EM and KP) independently read these papers. The third review author (LN) provided a third opinion when needed. We found no abstract or paper that required translation into English.

Selection criteria included randomised controlled trial, online support group and women with breast cancer (any stage). Additionally, we included studies that measured any of the primary outcomes (emotional distress, uncertainly, anxiety and depression) and the secondary outcome (quality of life).

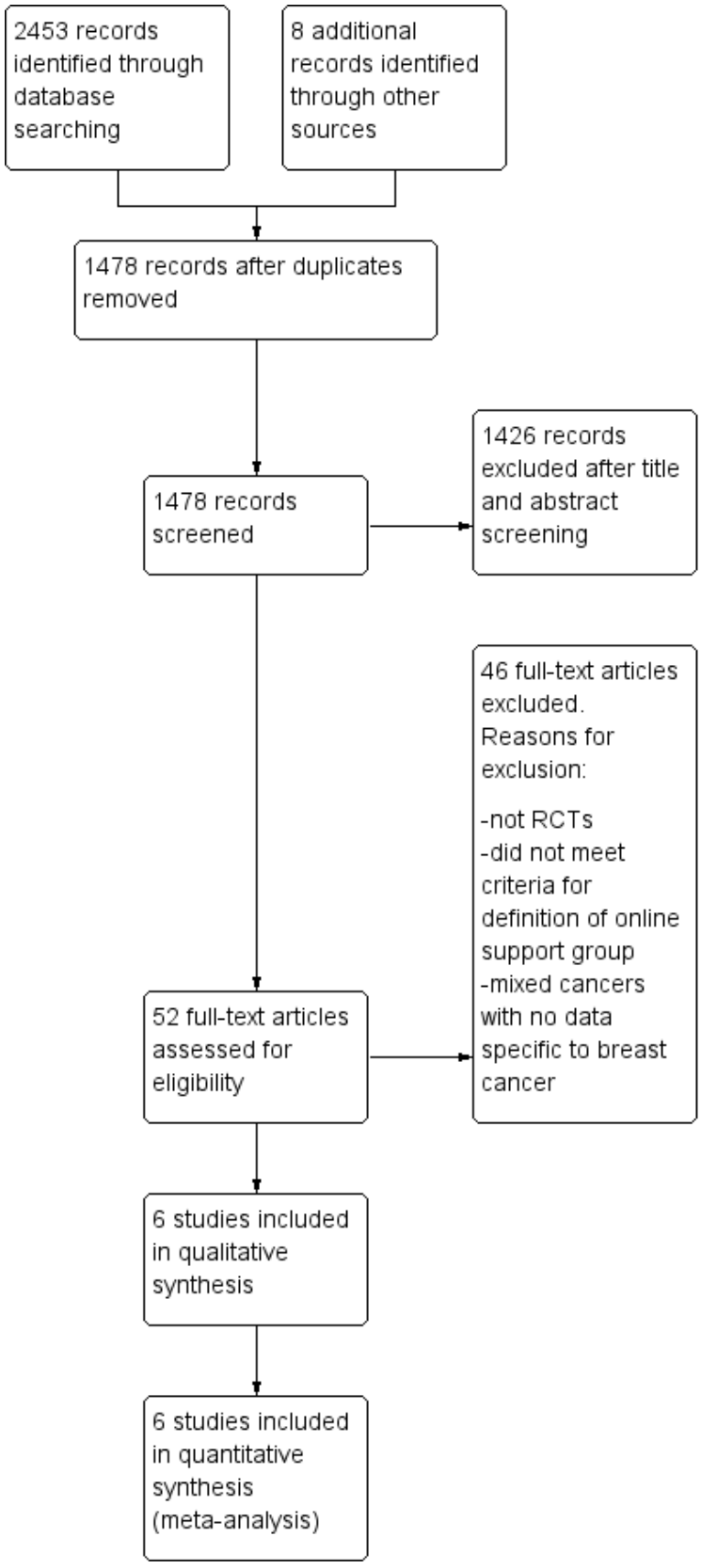
We noted excluded studies in the Characteristics of excluded studies table, along with reasons for exclusion.

### Data extraction and management

Two review authors (EM and KP) independently extracted data using a data extraction form developed for the purposes of this review. This form comprises items such as aims/objectives or hypotheses, study design (including randomisation method), sample (including age, ethnicity, setting and stage of cancer), follow-up, type and nature of online support group, dose, frequency, intensity or duration, outcomes (e.g. QoL, uncertainty), outcome measures, statistical tests and findings. A third review author (LN) was available to resolve differences when necessary.

We extracted data from all publications pertaining to the same study. We considered the main paper presenting the study design and most outcomes as the primary reference. Figure 1 shows the flow chart detailing the selection of studies.

**Figure 1. Study flow diagram.**



### Assessment of risk of bias in included studies

Two review authors (EM and KP) independently used the Cochrane 'Risk of bias' tool to assess risk of bias in the selected studies (Higgins 2011). A third review author (LN) resolved disagreements in ratings between these two review authors. We rated each of the following seven domains as having low, high or unclear risk of bias.

- Sequence generation.
- Allocation concealment.
- Blinding of participants and personnel.
- Blinding of outcome assessors.
- Incomplete outcome data.
- Selective outcome reporting.
- Other sources of bias.

We contacted five of the six study authors (Changrani 2008; Klemm 2012; Salzer 2010; Vilhauer 2010; Winzelberg 2003) to request missing information and received a reply from only one of them (Vilhauer 2010). We used outcomes of the risk of bias assessment to assess the quality of evidence for each outcome according to GRADE recommendations (Guyatt 2011).

### Measures of treatment effect

We considered all outcomes in the review (emotional distress, uncertainty, anxiety, depression and QoL) to be continuous outcomes. We used the mean difference (MD) or the standardised mean difference (SMD) together with 95% confidence intervals (CI), as appropriate. We obtained standard deviations (SDs) at baseline and at end of treatment from standard errors, CIs, t values or P values related to differences between means in the two groups (Higgins 2011). We compared means in intervention and control groups at follow-up for each group, using available data.

### Unit of analysis issues

We identified no cluster-randomised or cross-over trials. Three of the six included studies had more than one follow-up time point, but we could extract limited data for analysis from published papers or from study authors.

### Dealing with missing data

We contacted original study authors to request missing data and information on how they handled missing data when they conducted their data analyses, but we received only one response (as mentioned in Assessment of risk of bias in included studies section); no new information was available. When meta-analysis was not possible owing to missing data, we provided a narrative commentary.

### Assessment of heterogeneity

We noted the $Chi^2$ test (Cochran 1954) and the $I^2$ statistic (Higgins 2003) for two of the outcomes for which we found available data for pooling. We did not conduct a visual inspection of forest plots to assess statistical heterogeneity, as only two studies reported each of these two outcomes and they were similar in size. We narratively discussed different types of heterogeneity.

### Assessment of reporting biases

We identified too few studies to carry out funnel plots and the Egger test to assess reporting bias (Egger 1997).

### Data synthesis

We performed analysis using Review Manager 5 software (RevMan 2014) and used the inverse variance method to pool continuous measures (MDs) with a fixed-effect model (DerSimonian 1986).

For analysis, we grouped studies as intervention versus usual care (standard care). When the same study provided one or more interventions (and no usual care group), we reported study results narratively.

We used the GRADE approach to rate the quality of evidence; we used GRADEPro software to generate Summary of findings for the main comparison to report primary and secondary outcomes.

### Subgroup analysis and investigation of heterogeneity

Data were insufficient for review authors to carry out separate analyses for 'user-led' support groups and 'professional-led' support groups. For the same reason, we did not conduct subgroup analyses regarding sources of heterogeneity, such as stage of disease and types and doses of interventions.

### Sensitivity analysis

Studies and data were insufficient for review authors to perform a sensitivity analysis to assess robustness of results (e.g. excluding studies with high risk of bias).

## RESULTS

## Description of studies

### Results of the search

We conducted the search on 2 May 2016, and found 2453 records from the following databases: CBCG Specialised Register (194), CENTRAL (744), Embase (531), MEDLINE (273), PsycINFO (137) and the trial registries WHO ICTRP (32) and ClinicalTrials.gov (542). We found eight additional records from the reference lists of retrieved papers.

After removing duplicates, we screened the titles and abstracts of 1478 records. Fifty-two papers were potentially eligible, and the first two review authors read the full texts of these. We excluded 46 studies (see Excluded studies) and selected six studies (Changrani 2008; Klemm 2012; Lepore 2014; Salzer 2010; Vilhauer 2010; Winzelberg 2003) for inclusion in this review. Figure 1 outlines the selection process.

### Included studies

#### *Participants*

Investigators in the six included studies randomly allocated 492 women with breast cancer (mean 82; standard deviation (SD) 57.2; median 70; range 30 to 184) to online support or control groups. At final data collection time points, 416 participants (mean 69.3; SD 47; median 60; range 22 to 160) remained in the study, yielding an average attrition rate of 17.8% (range 13% to 27%). Slightly more participants dropped out of the intervention groups than out of the control groups, except in Vilhauer 2010, which reported that 35% dropped out of the waitlist group compared with 19% of the online support group.

Researchers allocated 277 participants to online support groups (mean 46; SD 27.5; median 42; range 16 to 96) compared with

215 to control groups (mean 35.8; SD 26.7; median 28.5; range 14 to 88). Two of the six studies (Changrani 2008; Salzer 2010) had approximately twice as many participants in the intervention group as in the control group.

Study authors carried out all six studies in the USA and recruited participants from different states. Investigators described three studies as 'pilot' (Salzer 2010), 'feasibility' (Changrani 2008) or 'feasibility pilot' (Vilhauer 2010).

Three studies (Klemm 2012; Lepore 2014; Salzer 2010) described more than 90% of participants as 'white'. Vilhauer 2010 had 100% 'white' participants, and Changrani 2008 described all participants as 'Hispanic'. Klemm 2012 reported 10% and Winzelberg 2003 4% 'Afro-Americans'. Only one study (Winzelberg 2003) included 'Asians' (6%).

Three studies provided no information on participant income, and the other three studies reported participant annual earnings of between 40,000 and 50,000 $USD. The mean reported annual income in one study was over 83,000 $USD. Most participants in four of the six studies completed education at high school level or higher. Winzelberg 2003 described participants as 'highly educated'. The remaining two studies (Changrani 2008; Klemm 2012) provided no information on educational attainment.

Salzer 2010 did not provide details on the age profile of participants but mentioned that almost 40% were younger than 50 years of age. The other five studies reported participant mean age of 50.7 years (standard deviation (SD) 2.56 years).

Two studies (Changrani 2008; Klemm 2012) recruited women at all stages of breast cancer, and two other studies (Lepore 2014; Salzer 2010) recruited participants at stages I and II of breast cancer. Vilhauer 2010 reported that all participants had metastatic breast cancer, and Winzelberg 2003 only described participants as having had a primary breast carcinoma diagnosis. Lepore 2014 recruited only participants with distress or depression levels ≥ 8 on the Hospital Anxiety and Depression Scale (HADS). Winzelberg 2003 provided no information on stage of treatment of participants. The other five studies reported that all participants were receiving one or more forms of treatment (surgery, chemotherapy, hormonal therapy or radiotherapy).

#### *Intervention*

Of the six included studies, four (Changrani 2008; Salzer 2010; Vilhauer 2010; Winzelberg 2003) included one intervention group and one control/waitlist group. Klemm 2012 provided only two interventions (a moderated online support group and a peer-led online support group). Lepore 2014 provided only two interventions (a standard Internet support group and an enhanced prosocial Internet support group). In all, the six included studies included eight intervention groups and four control/waitlist groups.

The aim of the four studies (Changrani 2008; Salzer 2010; Vilhauer 2010; Winzelberg 2003) that included one intervention and one control group was to find out whether Internet/online support groups improved psychosocial outcomes for women. These investigators also measured outcomes such as participation, satisfaction, personal growth and social support. The aim of the remaining two studies was to compare two different formats of Internet/online support groups in terms of the outcomes mentioned above. The aim of Klemm 2012 was to compare a moderated group versus a peer-led group. Lepore 2014 sought to compare a standard Internet support group (S-ISG) versus an enhanced prosocial Internet support group (P-ISG) and hypothesised that the P-ISG, which encouraged and facilitated participants to help others, would have a more positive impact than the S-ISG in reducing depression and anxiety.

Only three of the eight interventions in this review were peer led (Klemm 2012; Salzer 2010; Vilhauer 2010).

Facilitators in the included studies were trained bilingual (English and Spanish) professionals (Changrani 2008); Master's degree prepared social workers experienced in providing online and telephone help for people with cancer and their carers (Klemm 2012); graduate level health professionals with more than 10 years' experience running Internet support groups (Lepore 2014) and mental health professionals (Winzelberg 2003). The main role of moderators or facilitators was to provide structure to support groups while encouraging participants to talk about and share their views on issues (preselected or not) of concern to participants. Among studies that provided moderated online support groups, Changrani 2008 had 'no set agenda', Klemm 2012 had 'preselected topics', Lepore 2014 had 'chat topics' and Winzelberg 2003 included conversations around 'weekly topics'.

#### *Frequency and duration*

Five studies (Changrani 2008; Klemm 2012; Lepore 2014; Vilhauer 2010; Winzelberg 2003) provided detailed information about frequency and duration of the interventions, which ranged from six to 30 weeks. Salzer 2010 did not describe frequency and duration of the intervention. Two studies (Changrani 2008; Lepore 2014) reported that participants logged in for 1.5 hours per week, and two others (Klemm 2012; Vilhauer 2010) reported that participants logged in for 2.5 hours per week. Winzelberg 2003 did not describe the exact duration of the intervention but reported that participants logged in on average 34 times (SD 29; range 3 to 22) and posted an average of 36 support group messages (SD 38; range 1 to 146) over the 12-week duration of the intervention.

The size of support groups in each trial was as follows: Changrani 2008 - eight to 10; Klemm 2012 - up to 15; Lepore 2014 - 14 to 17; Vilhauer 2010 - 10 to 11; and Winzelberg 2003 - 10 to 15. Salzer 2010 provided no information on group size.

#### *Control group*

Included studies provided sparse information on control groups. Changrani 2008 provided 'usual care' to participants; Salzer 2010 gave participants information on a cancer-related website, and Vilhauer 2010 "sent a bi-weekly breast cancer newsletter by email" to participants in both intervention and control groups. In Winzelberg 2003, participants in the waitlist group "were invited to participate in their own support group". Two studies (Klemm 2012; Lepore 2014) included no control group.

Only one study (Vilhauer 2010) set "not being users of online groups" as an inclusion criterion. The same study reported that one participant was a regular user of an online support group and another "occasionally accessed a large online bulletin board for all kinds of cancer patients". Among participants in Winzelberg 2003, 34% were already participating in another breast cancer support group or were receiving individual counselling at baseline. The

other four studies (Changrani 2008; Klemm 2012; Lepore 2014; Salzer 2010) did not mention participation in other support groups in their selection criteria and did not report this information.

Four studies (Klemm 2012; Lepore 2014; Salzer 2010; Vilhauer 2010) specified access to computers and the Internet as an inclusion criterion. Changrani 2008 provided access to computers and the Internet as well as technical support for participants who did not have these facilities. Winzelberg 2003 reported that participants without access to a computer "were loaned, free of charge, a WebTV computer" and "were instructed on its use".

Finally, two studies (Lepore 2014; Salzer 2010) required that eligible participants had to be fluent in English, Klemm 2012 required that participants had to be "able to read and write English" and Winzelberg 2003 specified "being able to communicate in written English" as an inclusion criterion. In Changrani 2008, all participants were Spanish speaking. Vilhauer 2010 did not mention language as an inclusion criterion.

### Excluded studies

We excluded 46 studies (see PRISMA flow chart in Figure 1) because they were not randomised controlled trials, did not meet the inclusion criterion of providing an online support group or included breast cancer as well as other cancers but did not provide separate data related to breast cancer. Eleven studies (see Characteristics of excluded studies) initially appeared relevant to this review, but after further assessment, we excluded these 11 studies after independent assessment by two review authors (EM and KP) and discussion with another review author (LN). We excluded four studies (Badger 2013; Børøsund 2014; Owen 2005; Schover 2013) because investigators tested online interventions other than online support groups. We excluded three studies (Gustafson 2001; Gustafson 2008; Ruland 2013) that tested other types of online interventions but had an online support group component, because they did not provide separate data for online support groups. We excluded three other studies (Hoybye 2010; Klemm 2002; Stephen 2013) because they included participants with various cancers (including breast) but did not provide separate data for breast cancer. We excluded one study (Heiney 2012) because it included elements of support groups but did not report outcomes of interest for this review.

## Risk of bias in included studies

Refer to Figure 2 and Figure 3.

**Figure 2. Risk of bias graph: review authors' judgements about each risk of bias item presented as percentages across all included studies.**

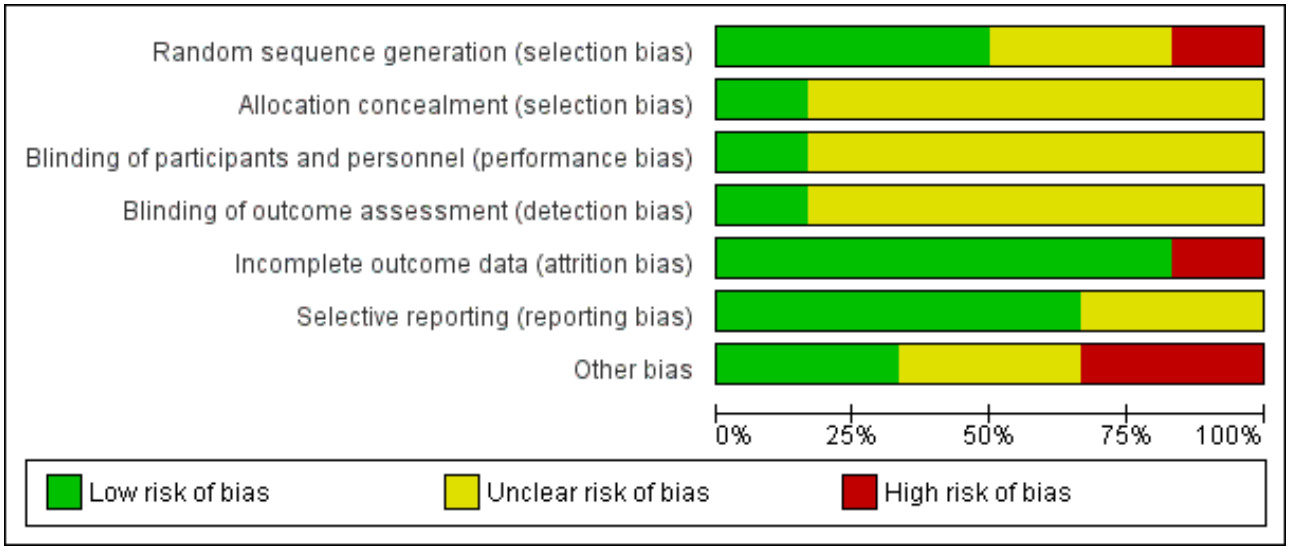
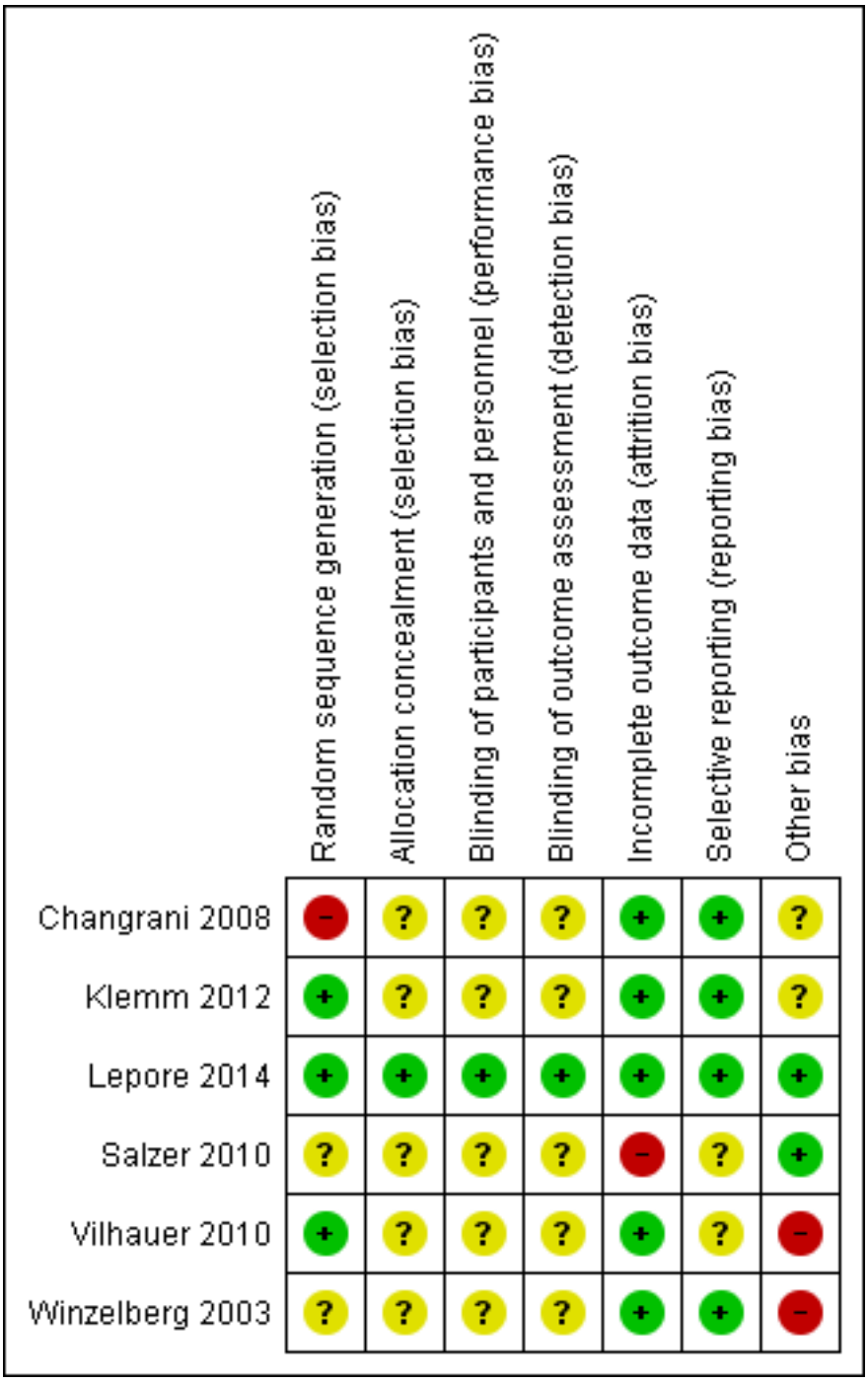


**Figure 3. Risk of bias summary: review authors' judgements about each risk of bias item for each included study.**




### Allocation

Three studies (Klemm 2012; Lepore 2014; Vilhauer 2010) used a 'coin flip' or a computer package to randomise participants to study groups and were therefore judged to be at low risk of bias. Changrani 2008 reported that "the randomisation protocol was compromised by selecting patients serially as they registered"; we judged this study to be at high risk of bias. The remaining two studies (Salzer 2010; Winzelberg 2003) reported that investigators randomly assigned participants to groups but did not explain how this happened; therefore, we judged these studies to be at unclear risk of bias.

One study (Lepore 2014) reported concealment of allocation by use of opaque envelopes and was assessed as being at low risk of bias. The other five studies provided no information on allocation concealment in published papers nor via personal communication; therefore, we classified these studies as having unclear risk of bias.

### Blinding

Blinding of participants to group allocation is problematic in studies involving support groups or other psychosocial interventions, as participants knew what they were receiving (and no placebo was involved). Therefore, it is not surprising that the authors of five studies (Changrani 2008; Klemm 2012; Salzer 2010; Vilhauer 2010; Winzelberg 2003) did not mention whether participants were blind to group allocation, nor whether personnel, in particular, support group moderators, were aware of group allocation; we judged these studies to be at unclear risk of bias. The remaining study (Lepore 2014) described that "participants and interventionists" were not told of the study hypotheses; therefore, we considered this study to be at low risk of bias.

Four studies (Changrani 2008; Klemm 2012; Salzer 2010; Winzelberg 2003) provided no information on whether data assessors were blinded to group allocation. In one study (Vilhauer 2010), the author stated that she carried out all data entry and analysis but could not say whether data assessment was blind to group allocation (personal communication). Therefore, we judged these studies as having unclear risk of bias. In the remaining study (Lepore 2014), "trained researchers, who were blind to condition" collected the data; therefore, we assessed this study as having low risk of bias.

### Incomplete outcome data

Researchers in five studies (Changrani 2008; Klemm 2012; Lepore 2014; Vilhauer 2010; Winzelberg 2003) provided information about participants lost during the study and reasons for attrition. These studies were assessed as having low risk of bias. One study (Salzer 2010) provided overall attrition rates at two time points, but did not provide data on how many participants in each group did not complete the study; it was assessed as having high risk of bias.

### Selective reporting

Four studies (Changrani 2008; Klemm 2012; Lepore 2014; Winzelberg 2003) reported all outcomes. We judged these studies to be at low risk of bias. Salzer 2010 reported outcome data but information on precise attrition in groups was missing, and Vilhauer 2010 did not provide detailed results at two months post intervention. We judged these two studies (Salzer 2010; Vilhauer 2010) to be at unclear risk of bias.

### Other potential sources of bias

Two studies (Lepore 2014; Salzer 2010) appeared to have no other potential sources of bias. We judged two studies (Changrani 2008; Klemm 2012) as having unclear risk of bias from other potential sources. Changrani 2008 was a small feasibility study that provided intentional, unequal allocation of participants to two study groups; and Klemm 2012 randomised women with more depressive symptoms to peer-led groups. We determined that the remaining two studies (Vilhauer 2010; Winzelberg 2003) were at high risk of bias from other potential sources. Vilhauer 2010 was a small feasibility study in which 43% of participants were attending face-to-face support groups and 20% were receiving individual psychotherapy; and Winzelberg 2003 reported that 34% of women were participating in another breast cancer support group and in individual counselling at baseline.

## Effects of interventions

See: **Summary of findings for the main comparison** Online support group for women with breast cancer

Refer to Summary of findings for the main comparison. The primary outcomes in this review were emotional distress, uncertainty, anxiety and depression. Quality of life was a secondary outcome.

### Emotional distress

None of the included studies measured 'emotional distress' as an outcome. Salzer 2010 used the Hopkins Symptoms Checklist (HSCL-25) and the Profile of Mood States (POMS) to measure 'distress' and used the Impact of Events Scale (IES) to measure 'cancer-specific distress'. They reported that participants (78 women) in the Internet peer-to-peer support group (intervention) "did worse" on these outcomes than those in the control group at four and 12 months post intervention.

### Uncertainty

None of the six included studies measured uncertainty as an outcome.

### Anxiety

Only two studies (Lepore 2014; Winzelberg 2003) measured anxiety as an outcome. Winzelberg 2003 used the 20-item State-Trait Anxiety Inventory (STAI) to measure anxiety as an outcome in a sample of 72 women with breast cancer when investigators compared a web-based support group versus a waitlist control group. Researchers reported no statistically significant change in anxiety (MD -0.40, 95% CI -6.42 to 5.62; Analysis 1.1) between the two groups. We rated the quality of evidence as low owing to unclear risk of bias regarding randomisation, blinding of participants and personnel and imprecision (small sample).

Lepore 2014 compared a standard Internet support group (S-ISG) with a prosocial Internet support group (P-ISG) for 184 women with breast cancer (see Characteristics of included studies) and used the seven items that measured anxiety in the HADS. Health professionals facilitated sessions for both groups, and the study included only distressed participants (scoring above normal (≥ 8) for levels of depression and anxiety on the HADS). For S-ISG, investigators "emphasized the exchange of information and emotional support between peers", and participants in enhanced P-ISG "received written tips on how to recognise and respond to others' need for support online" (p.4082). These researchers reported decreased symptoms of anxiety from baseline post intervention in both groups but noted that participants in the P-ISG did not do as well as those in the S-ISG, as they had hypothesised. Study authors commented that the lack of a usual control group prevented them "from estimating how much of symptom improvement was attributable to natural recovery" (p.4085).

### Depression

Five studies (Changrani 2008; Klemm 2012; Lepore 2014; Vilhauer 2010; Winzelberg 2003) reported depression as a study outcome. Lepore 2014 (184 women) used the HADS to measure depression, and the other four studies used the 20-item Center for Epidemiologic Studies Depression Scale (CESD). Three studies (Changrani 2008; Vilhauer 2010; Winzelberg 2003) included an online support group and a control group. Two studies (Klemm

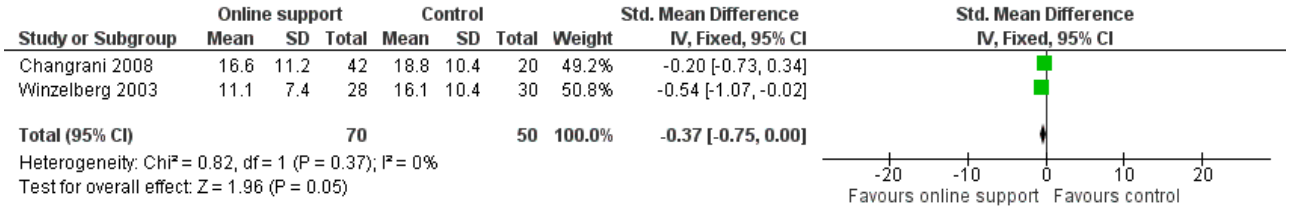
2012; Lepore 2014) included no control group - only comparison groups.

Vilhauer 2010 compared 'peer-to-peer' online support groups with a waitlist group and reported no difference in levels of depression post intervention. All participants were at the metastatic stage of breast cancer. This was a pilot study with a small sample size (30 women) and 27% attrition. No extractable data were available for analysis.

Changrani 2008 reported no statistically significant differences after comparing the effectiveness of an online support group versus a control group in reducing depression. Study authors described all participants (68 women) as "underserved immigrant Latinas".

Winzelberg 2003 included 72 women with breast cancer (most were highly educated, white women) and reported that its web-based support group intervention was more effective in reducing depression when compared with a "waitlist" control group. Data pooled from Changrani 2008 and Winzelberg 2003 showed a small to moderate decrease in depression among online support groups when compared with waitlist groups (SMD -0.37, 95% CI -0.75 to 0.00; two studies; 120 women; Analysis 1.2; Figure 4). We rated the quality of this evidence as very low owing to unclear risk of bias (compromised randomisation in one study (Changrani 2008) and lack of information on blinding of participants and personnel in both studies), imprecision (small sample) and inconsistency (population heterogeneity).

**Figure 4. Forest plot of comparison: 1 Online support group versus usual care, outcome: 1.2 Depression at end of intervention.**




Klemm 2012 included 60 women and used the CESD to compare "moderated" and "peer-led" online support groups at three time points (six, 12 and 16 weeks). Investigators hypothesised that women with breast cancer taking part in moderated online support groups (facilitated by social workers, with preselected topics for discussion each week) would experience fewer depressive symptoms when compared with those participating in a peer-led online support group. Results showed no significant differences (P > 0.05) between the two groups in depressive symptoms at the three time points. Study authors commented that the sample size may not have been large enough to permit detection of subtle changes in depressive symptoms.

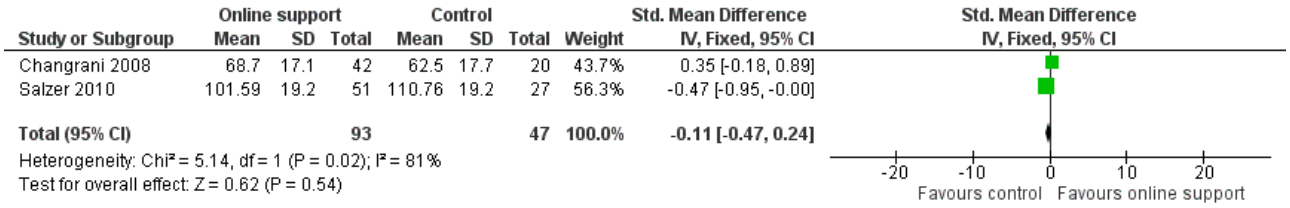
Lepore 2014 compared an S-ISG with a P-ISG for 184 women with breast cancer (see section on anxiety, above). Investigators used the HADS to measure depression and reported that both groups experienced a reduction in depression, but those in the S-ISG had significantly lower depression levels than those in the P-ISG. The absence of a usual care control makes it difficult to know how much this reduction in depression was due to natural recovery.

### Quality of life

Only three studies (Changrani 2008; Salzer 2010; Vilhauer 2010) measured quality of life; all used the Functional Assessment of Cancer Therapy – Breast Cancer (FACT-B). Vilhauer 2010 (30 women) reported no statistically significant differences in reported quality of life when comparing an online support group with a "waitlisted control condition" group. This study provided no extractable data for analysis. Changrani 2008 (68 women) reported no statistically significant differences in quality of life resulting from an online cancer group intervention when compared with control. Salzer 2010 (78 women) compared an Internet peer-to-peer support intervention versus a control and noted that participants in the Internet group reported lower quality of life than those in the control group at four months post intervention. They concluded that these findings should be treated with caution, as the study was "underpowered to detect small–moderate effects" (p.445).

Pooled data from Changrani 2008 and Salzer 2010 showed no significant change in quality of life at four months post intervention (SMD -0.11, 95% CI -0.47 to 0.24; Analysis 1.3; Figure 5). Salzer 2010 provided no standard deviations and used pooled SDs for calculations. Although this study provided an overall attrition rate at two time points, investigators did not provide clear data on how many participants in each group did not complete the study and used baseline figures in study calculations. We rated the quality of evidence from both Salzer 2010 and Changrani 2008 as very low owing to high or unclear risk of bias (compromised randomisation in one study (Changrani 2008), lack of information regarding concealment and blinding of participants and personnel in both studies), imprecision (small samples) and high statistical heterogeneity ($I^2$ = 81%). Only Salzer 2010 reported data on quality of life at 12 months post intervention, revealing a decrease in quality of life in the intervention group compared with the control group (MD -10.89, 95% CI -20.41 to -1.37; Analysis 1.4). We rated the quality of this evidence as low owing to unclear risk of bias (lack of information regarding randomisation, concealment and blinding of participants and personnel) and imprecision (small sample).

**Figure 5. Forest plot of comparison: 1 Online support group versus usual care, outcome: 1.3 Quality of life post intervention.**




None of the included studies mentioned adverse effects.

Data were insufficient for subgroup analysis on stage of disease, treatment modality and type and dose of interventions. Overall risk of bias in the included studies was unclear or low.

## DISCUSSION

### Summary of main results

None of the included studies measured emotional distress or uncertainty as an outcome of online support groups. Results showed no difference in anxiety levels between those who participated in online support groups and controls (based on low-quality evidence from one study). Two studies showed a small to moderate reduction in depression levels among participants in online support groups compared with controls, but we rated the quality of this evidence as very low. Pooled data from two studies showed no difference in quality of life among women with breast cancer at four months post intervention between online support groups and control groups; we rated the quality of this evidence as very low. Similarly, another study showed no difference in quality of life at four months on the basis of low-quality evidence.

Readers should treat the results of this review with caution as we obtained evidence regarding selected outcomes from a few small studies with several methodological weaknesses.

### Overall completeness and applicability of evidence

We found few studies with large enough samples to adequately address the objectives of this review. Investigators described three of the six included studies as 'pilot' or 'feasibility', and two of six studies included no control group but instead tested two different formats of online support groups. Not all included studies measured all of the outcomes in this review, and even fewer studies provided data on each outcome. The overall implication of underpowered trials is a scarcity of data from which to draw conclusions regarding effects of online support groups. Lack of extractable data for pooling and selective reporting added to the difficulties of this review.

Applicability of evidence from included studies should be put in the context of types of participants and interventions. In four of the six studies, 90% to 100% of participants were 'white'. One study described all participants as "underserved immigrant Latinas". The remaining study provided no information on ethnic background of participants. In the three studies that provided information on income, participants reported annual earnings of 40,000 to 50,000 $USD. The mean reported income in one study was over 83,000 $USD.

In four of the six studies that provided information about educational attainment, most participants had completed education at high school level or higher. The generalisability of review findings to an ethnically diverse, more deprived and less educated population (than participants in this review) is questionable. Generalisation to populations outside the USA (where all six studies were conducted) is also limited. Online support groups involve cultural norms and behaviours that are often specific to context. One of the authors of this review (Changrani 2008) explained that different cultures have different values. She compared traditional Western values, which stress the desirability of individualism, autonomy and competition, versus Hispanic cultural traditions, which emphasise the importance of collectivism, interdependence and cooperation.

Studies showed some degree of heterogeneity in terms of stage of disease. In one study, all participants were at the metastatic stage. Participants in all other included studies were at disease stages I and II. One study recruited only participants with distress and depression levels ≥ 8 on the Hospital Anxiety and Depression Scale (HADS). All participants received one or more forms of treatment.

Investigators also reported variation among interventions in terms of dose, frequency, content and format. Study duration ranged between six and 30 weeks. Participation in group sessions lasted between 90 and 142 minutes per week. Some sessions had 'no set agenda' and others focused on 'preselected' topics. Three of the eight interventions were peer led; social workers, health professionals or mental health workers moderated all others. In practice, variations among online support groups currently in operation are similar. Outcomes selected for this review (emotional distress, uncertainty, anxiety, depression and quality of life) seem to be more health professional centred than participant centred. Included studies also measured other outcomes such as participation, satisfaction, personal growth and social support.

### Quality of the evidence

We have reported details about potential sources of bias in the Characteristics of included studies table and in Summary of findings for the main comparison. Other weaknesses in the methods of most included studies may have compromised the integrity of these studies. With regards to anxiety, evidence from one large (184 participants) study (Lepore 2014) of high quality (see Risk of bias in included studies) shows that participants in the standard online support group reported less anxiety than those in the enhanced online support group of women with breast cancer. One study with 72 participants (Winzelberg 2003) provided evidence that online support groups did not reduce anxiety levels among women with cancer compared with control groups. Winzelberg 2003 reported that 34% of participants (9 control

and 13 intervention) were participating in another breast cancer support group or were receiving individual counselling at baseline. However, "no data were collected on posttest participation in psychologic interventions" (p.1166). Participation in other groups could have confounded the results of this study. On the basis of these limitations, as well as the risk of bias assessment (see Risk of bias in included studies) and evaluation of criteria in terms of GRADE assessment, we rated the quality of evidence (regarding anxiety) derived from this study as low.

Similarly, we obtained evidence that participants in online support groups had a small to moderate reduction in depression (when compared with controls) in two studies (total population: 120): Winzelberg 2003 and Changrani 2008. Changrani 2008 is a feasibility study in which investigators allocated twice as many participants to the experimental group. Changrani 2008 researchers pointed out that the "randomisation protocol was compromised by selecting patients serially as they registered" (p.61). Limitations of these two studies (Changrani 2008; Winzelberg 2003) could have reduced the strength of evidence related to depression. On the basis of these limitations, as well as the risk of bias assessment (see Risk of bias in included studies) and evaluation of criteria in terms of GRADE assessment, we rated the quality of evidence (regarding depression) derived from these studies as very low.

Two studies included comparison groups but no usual care control groups. One large, rigorously conducted study (Lepore 2014) with 184 participants showed a greater reduction in depression in the standard online support group than in the enhanced online support group for women with breast cancer. Klemm 2012 was the only study (total population: 60) that provided evidence of no difference in depressive symptoms between participants in 'moderated' and 'peer-led' groups. The report of study authors indicating that women with more depressive symptoms were randomised to the peer-led group revealed that this evidence was compromised.

Three studies measured quality of life. Two studies (Changrani 2008; Salzer 2010) with a total population of 140 provided evidence that online support groups did not affect the quality of life of women with breast cancer. We have pointed out the limitations of Changrani 2008. The second was a small study (Salzer 2010) in which investigators intentionally allocated twice as many participants to the experimental group. As a result, "the study was underpowered to detect small-moderate effects at $P < 0.05$ level" (p.445). Also, Salzer 2010 did not provide details of attrition in the two groups. On the basis of these limitations, along with the risk of bias assessment and evaluation of criteria in terms of GRADE assessment, we rated the quality of evidence (regarding quality of life at four months post intervention) as very low. Similarly, we rated evidence from this trial suggesting that quality of life did not improve at 12 months post intervention as low. The third study (Vilhauer 2010) was a 'feasibility pilot' study with a small sample (n = 30), in which investigators reported that 43% of participants were attending face-to-face support groups, and 20% individual psychotherapy. Results showed higher attrition at the end of the intervention in the control group (36%) than in the experimental group (19%). These factors could have introduced bias and confounders. This study did not provide extractable data for pooling, but study authors reported no differences between intervention and control groups.

### Potential biases in the review process

A potential limitation of reviews in general involves missing key studies. Although we carried out an extensive search of the literature at the start of this review, the search for studies that could have been missed did not end until the review was completed. Most journals offer online facilities to help readers search for 'related articles' or similar articles from the same study authors. Use of these tools, as well as perusal of the reference lists of relevant studies and reviews, provided opportunities to validate results of the main search and to find new papers.

Another factor that may have affected the results of this review is the non-availability of relevant studies published in the public domain (i.e. grey literature). Researchers conducted all included studies in the USA and published study findings in the English language. The possibility exists that relevant studies may have been carried out in other countries and published in languages other than English.

Although we contacted all but one of the included study authors, only one responded. Non-availability of key data and information needed to clarify the trial process was beyond the control of the authors of this review (and of some authors of these studies, as some studies were conducted longer than a decade ago). If all data for pooling and other information had been available, results of this review may have been different.

Outcomes selected for reviews often reflect the interests of the review authors and, to some extent, what is available in the literature. Other outcomes such as 'patient satisfaction', 'connecting with others' and 'empowerment' may have presented online support groups in a different light.

With hindsight, we believe it would have been useful to include studies with other designs along with randomised controlled trials. Findings of these studies may have added strength to the review conclusions, although lack of controls would have added to the inconclusiveness of the evidence. We propose to be more inclusive in our selection criteria in future updates of this review.

Defining online support groups, as well as choosing to exclude studies of interventions that included some elements of support groups along with therapy, training or services, was a subjective exercise, albeit carried out collectively by the authors of this review. Others undertaking this review may have been more inclusive than we have been. We deliberated for a long time as to whether we should include 'high-intensity' interventions that were in fact 'psychosocial interventions'. We decided to exclude them to protect the integrity and focus of our review (i.e. online support groups for women with breast cancer, whether led by participants or health professionals). Inclusion of 'high-intensity interventions' in this review would have added heterogeneity and further diluted review findings. Scope and opportunity exist for a systematic review of online psychosocial interventions for women with breast cancer.

### Agreements and disagreements with other studies or reviews

In this section, we compare studies of online support groups for women with breast cancer that used a design other than a randomised controlled trial. We also compare the findings of this review with those of relevant systematic reviews.

Lieberman 2003 was a pretest/post-test study including 32 participants at all stages of breast cancer. They reported that participants' depression (as measured by the Center for Epidemiologic Studies Depression Scale (CESD)) was "significantly reduced". This study lacked randomisation and control. Another pre-test/post-test study (Battenburg 2014) of 133 Dutch women with breast cancer reported that depression did not change significantly from baseline to six months after participation in an online peer-led support group. This study had no control group.

A literature review on online cancer support groups (Klemm 2003) identified 10 studies, of which six focused on women with breast cancer. None of these studies included randomisation to groups, and none included control groups. The review revealed one study (Kraut 1998) in which investigators found that more time spent on the Internet led to higher levels of depression among participants. Internet use, in this case, referred to all types of social interactions conducted via the Internet, including participation in online groups. However, Klemm 2003 did not report specifically the effect of online support groups on depression.

Systematic reviews of support group studies of participants with cancer have reported that most of these studies involved women with breast cancer (Hoey 2008; Hong 2012). Hoey 2008 was a systematic review of peer support programmes for people with cancer, including face-to-face and online programmes. Studies included in this review were descriptive (n = 26), non-randomised (n = 8) and randomised controlled trials (n = 8). Evidence of psychosocial benefit was mixed, and randomised controlled trials reported no significant effects on quality of life. In a systematic review of online support and resources for cancer survivors (Hong 2012), 14 of the 24 included studies focused on women with breast cancer, and only four of the 24 studies used a randomised controlled trial design. Although most of the included studies reported positive effects on psychosocial outcomes, none of the randomised controlled trials reported significant positive outcomes.

A systematic review (Griffiths 2009) of depression-specific online support group studies (n = 28) included participants with cancer and those with other conditions such as mental disorder, diabetes and kidney disease requiring dialysis. However, Internet support groups focused more on patients with breast cancer than on patients with any other condition. Results showed that peer-to-peer Internet support groups had a positive effect on depressive symptoms; however, only two of the 17 studies reporting this effect had used a controlled trial design. Of the five studies that involved women with breast cancer, three reported significant moderate to large effects on depression, and only one (Winzelberg 2003) was a randomised controlled trial. Griffiths 2009 concluded that breast cancer online support groups were more likely to be associated with positive results with regards to depression than were online support groups for other patients.

All three systematic reviews (Griffiths 2009; Hoey 2008; Hong 2012) described methodological weaknesses in most of the studies that used a randomised controlled trial design. Griffiths 2009, in particular, concluded that the "most salient finding" of this review "was the paucity of high-quality studies". This finding is significant because review authors reported "a trend toward an association between lower design quality and positive outcomes" (Griffiths 2009).

Overall, evidence from these studies and from systematic reviews indicates that online supports may have a positive effect on depression, although this finding is by no means conclusive. Results of the present review also showed a small to moderate reduction in depression, albeit from two studies with methodological weaknesses. Both this review and that of Hoey 2008 concluded that support groups did not have significant effects on quality of life. We found no systematic reviews against which to compare results of this review for the other outcomes (emotional distress, uncertainty and anxiety). These three systematic reviews (Griffiths 2009; Hoey 2008; Hong 2012) and this current review concur that large and robust studies on the effectiveness of online support groups for women with breast cancer are needed.

## AUTHORS' CONCLUSIONS

### Implications for practice

This review did not provide the evidence required to show whether participation in online support groups is beneficial for women with breast cancer because included trials were small studies of low or very low quality. Also, the samples included in these studies were heterogeneous in terms of stage of breast cancer and structure, format and content of included groups. Most of the women in these trials were in early stages of recovery, although in one study (Vilhauer 2010), all participants were at the metastatic stage. Small to moderate positive effects on depression reported by two studies with methodological weaknesses are encouraging but are not sufficient to justify firm recommendations for practice. The samples in most of the included studies were not ethnically diverse and included a disproportionate number of well-educated and above average income earners. Therefore, generalising the findings of this review to all women with breast cancer is unwise.

Review authors have not ruled out the possibility that online support groups may cause some harm. In two of the included studies, some outcomes for the control group were better than for the experimental group, although these findings were not statistically significant. None of the included studies measured adverse effects. Salzer 2010 reported a few incidents when some participants informed the group that their cancer had spread, and suggested that this may have affected depression and quality of life levels of the group.

In real life, online support groups can be viewed as a journey, especially if they last weeks or months, during which time participants will experience positive and negative emotions. Lack of focus on adverse effects of online support groups prevents any firm recommendations to practitioners regarding what they should advise women with breast cancer to expect if they embark on this journey.

Many women given a diagnosis of breast cancer may have joined a support group (face-to-face or online) or will do so in the future. They also will likely access a range of resources and support, simultaneously or concurrently, during their cancer journey. Some may take an active part and others may be 'lurkers' or may 'dip in and out' according to their needs. Health professionals should be aware of the benefits and drawbacks of different support resources so they can advise patients.

## Implications for research

Results of this review and of the systematic reviews mentioned in the section on Agreements and disagreements with other studies or reviews show that large and rigorous studies are needed to provide evidence on the effectiveness of online support groups for women with breast cancer. Only one study (Lepore 2014) included an adequate sample, and three studies were described as 'pilot' or 'feasibility'. Most participants were 'whites', and many included studies lacked rigour (Risk of bias in included studies). Future researchers should pay more heed to randomisation, allocation concealment and assessment of outcome procedures. They should ensure that groups are similar in important aspects such as level of depression or quality of life at baseline, and that those recruited are not participating in other online support groups at the time of the experiment. They must track control groups to find out what resources or support services they access, and whether they participate in other groups while participating in a study. Only one study included in this review (Vilhauer 2010) stipulated that users of other online groups had been excluded. Therefore, large, robust trials with ethnically and economically diverse participants are needed.

Investigators conducted all of the studies included in this review in the USA. Different socio-cultural factors (such as family and social networks) and health systems, including service provision, could have affected participation in online support groups as well as the benefits or harms derived from them.

Future researchers must explore adverse effects of participation in online support groups to inform practitioners who are giving advice to potential online support group users, so they can let patients know what they should expect.

Although results of this review show little effect on psychosocial outcomes measured in the included studies, other data collected by researchers in these trials tend to highlight the benefits provided to women who took part in online support groups. Changrani 2008 reported that feedback from participants was "overwhelmingly encouraging", and that they (participants) had opportunities to "undrown themselves" (p.60). Ninety-five per cent of participants in Vilhauer 2010 reported that the online support group had been helpful to them, and that they wanted to continue to communicate with group members after the study ended. In Salzer 2010, some participants took the initiative to continue the online support group after completion of the study. Winzelberg 2003 pointed out that "participants expressed a level of enthusiasm and concern for one another that was not captured by self-report measures" (p.1170). Some went on to develop their own online support group after the study ended. These findings must be explored. It is possible that targeting both reductions in anxiety or depression and improvement in quality of life is unrealistic. In one study (Winzelberg 2003), in which anxiety was not reduced following participation in an online support group, the study author concluded that the online support group did not directly address anxiety management.

Researchers should also explore the choice of outcomes to be measured. None of the included studies measured 'uncertainty'. This is surprising because uncertainty is perhaps one of the most common effects following a cancer diagnosis, lasting until well after completion of treatment. Fear of what to expect, including the possibility of recurrence, once a diagnosis of cancer is made and the need to compare cancer experiences with others in similar situations have been well documented in the literature (Dockery 2014; McCaughan 2011; Miller 2012).

Vilhauer 2010 suggested that some of the benefits of participation described by many women in their study in interviews and qualitative questionnaires may have eluded assessment through standard "quantitative measures" (p.580). She added that psychometric questionnaires may be less sensitive than interviews to clinical improvement after intervention. Klemm 2012 commented that the CESD (used to measure depression) is clinically relevant but may not capture subtle changes over time, and that maintaining participants' level of well-being or achieving small changes in depression or anxiety would be a more realistic target. Moreover, smaller samples and underpowered studies are unlikely to detect such changes. Work remains to be done regarding appropriate outcomes for measurement and appropriate tools with which to do this.

Finally, more can be done to improve the quality of reporting. Researchers should be expected to provide data on all measured outcomes in a form that allows comparison and pooling with findings of other studies. They should use CONSORT diagrams to show accurately the number of participants enrolled in the study and the level of attrition at different time points.

## ACKNOWLEDGEMENTS

We would like to acknowledge the contribution of the Cochrane Breast Cancer Editorial Group to this review.

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## CHARACTERISTICS OF STUDIES

### Characteristics of included studies *[ordered by study ID]*

#### Changrani 2008

| | |
|---|---|
| Methods | **Study design:** randomised controlled trial<br><br>**Follow-up:** post intervention only |
| Participants | Sixty-eight women with breast cancer (awaiting surgery, receiving active treatment or recovered) were randomly allocated to an experimental group (n = 48) or a usual care group (n = 20). All women were described by the study author as "underserved immigrant Latinas". All lived in the USA at the time of the trial. Mean age of participants was 46.2 for the experimental group and 50.8 for the control group. Mean years spent in the United States was 16.7, with a range of 0.25 to 43 years. No details of inclusion or exclusion criteria were given. Participants were recruited from a virtual community for immigrants with cancer in New York, USA. The attrition rate (did not complete) was 13% |
| Interventions | Intervention was provided in the form of online support groups that provided informational, emotional and social network support for women. Support groups were held for 90 minutes and consisted of 8 participants meeting once a week for 30 weeks. These sessions were facilitated by trained bilingual professional facilitators who did not have a set agenda for the sessions. Discussions ranged from managing symptoms and side effects of medication to family concerns and alienation<br><br>Control group participants received only usual care |
| Outcomes | **Depression**<br><br>Center for Epidemiologic Studies Depression Scale (CESD) (20-item)<br><br>**Quality of life**<br><br>Functional Analysis of Cancer Therapy (FACT-B, Spanish version) |
| Notes | |

***Risk of bias***

| Bias | Authors' judgement | Support for judgement |
|---|---|---|
| Random sequence generation (selection bias) | High risk | "The randomization protocol was compromised by selecting patients serially as they registered" (p.61) |

**Changrani 2008** *(Continued)*

| | | |
|---|---|---|
| Allocation concealment (selection bias) | Unclear risk | No information provided |
| Blinding of participants and personnel (performance bias)<br>All outcomes | Unclear risk | No information provided |
| Blinding of outcome assessment (detection bias)<br>All outcomes | Unclear risk | No information provided |
| Incomplete outcome data (attrition bias)<br>All outcomes | Low risk | Reasons for attrition given |
| Selective reporting (reporting bias) | Low risk | All outcome data reported |
| Other bias | Unclear risk | Feasibility study; small sample with unequal allocation to groups |

**Klemm 2012**

| | |
|---|---|
| Methods | **Study design:** randomised controlled trial<br>**Follow-up:** 6, 12 and 16 weeks |
| Participants | Sixty women with breast cancer (stages I to IV; 68% in stages I and II) were randomly allocated to a moderated or a peer-led online support group (30 in each). Mean age was 52.95 (M) and 51.57 (peer-led). Eligibility criteria included women who were at least 21 years old, had Internet access, were able to read and write English and had completed treatment in the 32 months before participation. Ninety per cent were 'white' and 10% 'African American'. Participants were recruited from Delaware, USA |
| Interventions | Moderated online support group was conducted in a semi-structured (psychoeducational) format via synchronous communication. The group was moderated by master's degree prepared social workers with experience in providing online and telephone help for people with cancer and their caregivers. The 12-week sessions included a range of preselected topics of relevance to these women<br>Peer-led online support group was run by participants themselves without preselected topics or input from a moderator. Both interventions lasted 12 weeks. The primary responsibility of the moderator was to introduce weekly topics and facilitate discussion among group members |
| Outcomes | **Depression**<br>CESD (20-item) |
| Notes | |

***Risk of bias***

| Bias | Authors' judgement | Support for judgement |
|---|---|---|
| Random sequence generation (selection bias) | Low risk | "A coin flip determined the type of group" (p.12) |

**Klemm 2012** *(Continued)*

| | | |
|---|---|---|
| Allocation concealment (selection bias) | Unclear risk | No information provided |
| Blinding of participants and personnel (performance bias)<br>All outcomes | Unclear risk | No information provided |
| Blinding of outcome assessment (detection bias)<br>All outcomes | Unclear risk | Although participants completed questionnaires online, no indication who analysed the data and were blinded to group allocation |
| Incomplete outcome data (attrition bias)<br>All outcomes | Low risk | Attrition was similar in both groups as were reasons for attrition |
| Selective reporting (reporting bias) | Low risk | All outcomes data were reported |
| Other bias | Unclear risk | Women with more depressive symptoms were randomised to peer-led groups |

**Lepore 2014**

| | |
|---|---|
| Methods | **Study design:** randomised controlled trial<br><br>**Follow-up:** 1 month post intervention |
| Participants | A total of 184 women with stages I and II breast cancer were randomly allocated to a standard Internet support group (S-ISG; n = 96) or an enhanced prosocial Internet support group (P-ISG; n = 88). Eligibility criteria were stage I or II breast cancer in the past 36 months; age 21 to 65; Internet access; fluency in English; and distress level ≥ 8 (above normal) for depression or anxiety on the Hospital Anxiety and Depression Scale (HADS). Participants were recruited from a State Cancer Tumor Registry in the USA<br><br>Attrition rate was 13%. Mean age of participants was 52.73 (S-ISG) and 51.75 (P-ISG). Ninety-five per cent of participants were described as 'white'. Ethnicity of the rest was not given |
| Interventions | This RCT had 2 interventions (S-ISG and P-ISG) but no usual care control. Both groups had a 90-minute live (synchronous) chat for 6 weeks. Facilitator introduced chat topics, which included the following: pain, fatigue, lymphoedema, self-esteem, body image, problems with physical activities, intimacy, sexuality, depression, anxiety, recurrence, fear and health challenges (e.g. diet, exercise, surveillance)<br><br>Differences between these 2 groups were as follows: Participants in the P-ISG group received written tips on how to recognise and respond to others' need for online support. They also received weekly emails describing chat topics and providing instructions to prepare 1 or 2 sentences on how their experiences with the chat topic might help others to cope |
| Outcomes | **Depression**<br><br>Hospital Anxiety and Depression Scale (HADS)<br><br>**Anxiety**<br><br>Hospital Anxiety and Depression Scale (HADS) |
| Notes | |
| ***Risk of bias*** | |

**Lepore 2014** *(Continued)*

| Bias | Authors' judgement | Support for judgement |
|---|---|---|
| Random sequence generation (selection bias) | Low risk | Stata 13.1 was used to generate random numbers (p.4082) |
| Allocation concealment (selection bias) | Low risk | "Allocations were recorded on paper sealed in opaque envelopes controlled by a project director" (p.4082) |
| Blinding of participants and personnel (performance bias)<br>All outcomes | Low risk | "Interventionists and participants were not told the study hypotheses" (p.4085) |
| Blinding of outcome assessment (detection bias)<br>All outcomes | Low risk | Trained researchers "who were blind to condition" collected the data (p.4092) |
| Incomplete outcome data (attrition bias)<br>All outcomes | Low risk | "Baseline variables did not differ significantly between participants who were lost to follow-up and participants who completed the study" (p.4083) |
| Selective reporting (reporting bias) | Low risk | All outcomes data were reported |
| Other bias | Low risk | None |

**Salzer 2010**

| | |
|---|---|
| Methods | **Study design:** randomised controlled trial<br><br>**Follow-up:** 4 months and 12 months, post intervention |
| Participants | Seventy-eight women with stage I and II breast cancer were randomly allocated to an Internet peer support condition (n = 51) or an Internet-based educational control condition (n = 27). Inclusion criteria were as follows: 18 years of age or older, diagnosis of stage I or II breast cancer within the preceding 12 months, access to a computer and the Internet, US resident and fluent in English<br><br>Almost 40% of participants were younger than 50 years of age, and 92% were described as 'white'. No information was given on the other 8%. Attrition rate at 12 months was 18%. All participants were US residents |
| Interventions | Participants in the Internet peer support condition were "subscribed to an unmoderated (i.e. no professional facilitator), closed Listserv". Those in the Internet-based education control condition reviewed information on a cancer-related website. Descriptions of the interventions were sparse |
| Outcomes | **Quality of life**<br><br>Functional Analysis of Cancer Therapy - Breast Cancer (FACT-B)<br><br>**Distress**<br><br>Hopkins Symptoms Checklist (HSCL-25)<br><br>Impact of Events Scale (IES)<br><br>Profile of Mood States (POMS) |

**Salzer 2010** *(Continued)*

| | |
|---|---|
| Notes | No standard deviation (SD) data were provided. The standard error of difference (SED) was calculated from the t-test statistic and the mean difference (d) (standard error of difference calculated as d/t-statistic). We then assumed that the SD was the same in both groups and calculated that common SD from the SED using the standard formula |

***Risk of bias***

| Bias | Authors' judgement | Support for judgement |
|---|---|---|
| Random sequence generation (selection bias) | Unclear risk | "Intentional unequal random assignment was used to generate a high enough flow of Listserv communication to produce an effect" (p.442). No further information about randomisation was provided |
| Allocation concealment (selection bias) | Unclear risk | No information provided |
| Blinding of participants and personnel (performance bias)<br>All outcomes | Unclear risk | No information provided |
| Blinding of outcome assessment (detection bias)<br>All outcomes | Unclear risk | No information provided |
| Incomplete outcome data (attrition bias)<br>All outcomes | High risk | No reasons for attrition given |
| Selective reporting (reporting bias) | Unclear risk | All outcome data were reported but information on precise attrition in groups was missing |
| Other bias | Low risk | None |

**Vilhauer 2010**

| | |
|---|---|
| Methods | **Design:** randomised controlled trial<br><br>**Follow-up:** monthly (for 6 months), post intervention |
| Participants | Thirty women with metastatic breast cancer were allocated to a peer-to-peer online support group (n = 16) or a waitlist control group (n = 14). Inclusion criteria were as follows: no concurrent medical condition likely to affect quality of life; no diagnosis of psychiatric illness before diagnosis of metastasis; continuous access to a computer and email; familiarity with using email; and not a regular user of other online metastatic breast cancer groups. Overall attrition rate was 27% (50% in experimental group). Mean age of participants was 52.7 years, and all were described as 'white'. Participants were from 15 states in the USA |
| Interventions | Participants who were enrolled in the online support group received a welcome email message and instructions on how to access the support group by email. They were informed of the structure of the group and were asked to adhere to the basic etiquette of respect, courtesy and sensitivity. Online support groups were not moderated, but participants were encouraged to write about positive and negative experiences. Each group was restricted to 10 or 11 members. On average, participants reported spending 60 minutes per week writing to the group and 82 minutes per week reading messages. Study lasted 6 months |

**Vilhauer 2010** *(Continued)*

| | |
|---|---|
| Outcomes | **Quality of life**<br>Functional Analysis of Cancer Therapy (FACT-B)<br>**Depression**<br>Center for Epidemiologic Studies Depression Scale (CESD) |
| Notes | |

***Risk of bias***

| Bias | Authors' judgement | Support for judgement |
|---|---|---|
| Random sequence generation (selection bias) | Low risk | Assigned to groups via a coin toss (p.565) |
| Allocation concealment (selection bias) | Unclear risk | No information provided |
| Blinding of participants and personnel (performance bias)<br>All outcomes | Unclear risk | No information provided |
| Blinding of outcome assessment (detection bias)<br>All outcomes | Unclear risk | "I am not sure that I could say data assessment was blind to group allocation as I did a lot of data entry" (email communication with study author) |
| Incomplete outcome data (attrition bias)<br>All outcomes | Low risk | Reasons for attrition given |
| Selective reporting (reporting bias) | Unclear risk | Detailed results at 2 months post intervention not given |
| Other bias | High risk | Very small sample; 43% attended face-to-face support groups, and 20% individual psychotherapy |

**Winzelberg 2003**

| | |
|---|---|
| Methods | **Design:** randomised controlled trial<br>**Follow-up:** once, post intervention |
| Participants | Seventy-two women with primary breast cancer were randomly allocated to a web-based social control group (Bosom Buddies) or to a waitlist control group (36 in each group). Eligibility criteria were as follows: female, receiving a primary breast carcinoma diagnosis within the past 32 months, no suicidal ideation, living in California and able to communicate in written English Attrition rate was 19.4%<br>Mean age of participants was 49.5 years. Ethnic composition was as follows: 81% white, 4% Afro-American, 4% Asian, 6% Hispanic and 6% 'other'. All participants were recruited from California, USA |
| Interventions | Intervention (Bosom Buddies) was a 12-week, structured, web-based support group moderated by a mental health professional. Each week, the facilitator introduced a new topic and participants were encouraged to express, openly and honestly, their thoughts and emotions, to receive and offer support and to learn new ways to cope with cancer. Group members could log on at any time to read and post |

**Winzelberg 2003** *(Continued)*

| | |
|---|---|
| | comments. The group was not meant to serve as a form of psychotherapy or as an alternative to psychotherapy. The moderator's primary task was to keep the conversation on the theme of the weekly topic and to encourage members to support one another<br><br>Participants allocated to the waitlist control group were asked to participate in their own support group intervention |
| Outcomes | **Depression**<br><br>Center for Epidemiologic Studies Depression Scale (CESD)<br><br>**Anxiety**<br><br>State Trait Anxiety Inventory (STAI) (20-item) |
| Notes | |

***Risk of bias***

| Bias | Authors' judgement | Support for judgement |
|---|---|---|
| Random sequence generation (selection bias) | Unclear risk | "Participants were randomly assigned" (p.1166), but further information was provided |
| Allocation concealment (selection bias) | Unclear risk | No information provided |
| Blinding of participants and personnel (performance bias)<br>All outcomes | Unclear risk | No information provided |
| Blinding of outcome assessment (detection bias)<br>All outcomes | Unclear risk | No information provided |
| Incomplete outcome data (attrition bias)<br>All outcomes | Low risk | "No significant differences were found between dropouts and those who did not drop out on any baseline measures" (p.1169) |
| Selective reporting (reporting bias) | Low risk | All outcomes were reported |
| Other bias | High risk | "Thirty-four percent of participants were participating in another breast cancer support group or individual counseling at baseline" (p.1166) |

CESD: Center for Epidemiologic Studies Depression Scale
FACT-B: Functional Assessment of Cancer Therapy - Breast Cancer
HADS: Hospital Anxiety and Depression Scale
HSCL-25: Hopkins Symptoms Checklist
IES: Impact of Events Scale
P-ISG: enhanced prosocial Internet support group
POMS: Profile of Mood States
RCT: randomised controlled trial
SD: standard deviation
SED: standard error of deviation
S-ISG: standard Internet support group
STAI: State-Trait Anxiety Inventory

**Characteristics of excluded studies** *[ordered by study ID]*

| Study | Reason for exclusion |
|---|---|
| Badger 2013 | This study tests telephone-based and video-based psychosocial interventions and does not meet the criterion of an online support group |
| Børøsund 2014 | This study evaluates an 'Internet-based patient provider communication service'. Although it includes an online forum group discussion, it does not meet the criterion of an online support group |
| Gustafson 2001 | This study evaluates the effectiveness of a Comprehensive Health Enhancement Support System (CHESS), which is described as an Internet-based "integrated and comprehensive system of services" (Gustafson 2008), including information provision, access to experts to answer patient questions, assessment of emotional status and tailored advice on coping, as well as online discussion groups of patients and families. We excluded this study because it comprised a service provision as well as an online support group, making it difficult to disentangle the effects of service provision from those of the online support group |
| Gustafson 2008 | Same as above (Gustafson 2001) |
| Heiney 2012 | This is a study of a therapeutic group conducted by teleconference. All participants are 'African Americans'. The study includes elements of support groups but does not provide data on the outcomes reported in this review |
| Hoybye 2010 | This online support group study includes participants with various cancers, including breast cancer. No separate data on breast cancer are presented, nor are they available from the study author |
| Klemm 2002 | This study compares traditional face-to-face prostate support groups with Internet support groups with different cancer diagnoses, including breast cancer. No separate data for breast cancer are available |
| Owen 2005 | Intervention Includes coping skills training; study does not meet the criterion of an online support group |
| Ruland 2013 | Intervention (WebChoice) in this study includes "an Internet-based interactive health communication application that allows cancer patients to monitor their symptoms and problems, provides individually tailored information and self-management support, e-communication with expert cancer nurses, and an e-forum for group discussion with other patients" (p.6). It does not meet the criterion of an online support group |
| Schover 2013 | This study compares a group of women with breast cancer who access a website called 'Tendril 8' (Sexual Renewal for Women After Cancer) with another group who access the website and receive supplemental sexual counselling. It does not meet the criterion of an online support group |
| Stephen 2013 | CancerChatCanada is an Internet-based, professional-led live-chat support group project for patients with cancer and their families. These online support groups comprise participants with various cancers, including breast cancer. Separate data on participants with breast cancer are not available in the paper nor from the study author |

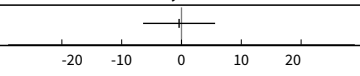
## DATA AND ANALYSES

## Comparison 1. Online support group versus usual care

| Outcome or subgroup title | No. of studies | No. of participants | Statistical method | Effect size |
|---|---|---|---|---|
| 1 Anxiety at end of intervention | 1 | | Mean Difference (IV, Fixed, 95% CI) | Subtotals only |
| 2 Depression at end of intervention | 2 | 120 | Std. Mean Difference (IV, Fixed, 95% CI) | -0.37 [-0.75, 0.00] |
| 3 Quality of life post intervention | 2 | 140 | Std. Mean Difference (IV, Fixed, 95% CI) | -0.11 [-0.47, 0.24] |
| 4 Quality of life 12 months post intervention | 1 | | Mean Difference (IV, Fixed, 95% CI) | Subtotals only |

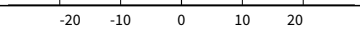
### Analysis 1.1. Comparison 1 Online support group versus usual care, Outcome 1 Anxiety at end of intervention.

| Study or subgroup | Online support | | Control | | Mean Difference | Weight | Mean Difference |
|---|---|---|---|---|---|---|---|
| | N | Mean(SD) | N | Mean(SD) | Fixed, 95% CI | | Fixed, 95% CI |
| Winzelberg 2003 | 28 | 47.8 (12.7) | 30 | 48.2 (10.5) | | 0% | -0.4[-6.42,5.62] |



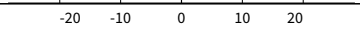

### Analysis 1.2. Comparison 1 Online support group versus usual care, Outcome 2 Depression at end of intervention.

| Study or subgroup | Online support | | Control | | Std. Mean Difference | Weight | Std. Mean Difference |
|---|---|---|---|---|---|---|---|
| | N | Mean(SD) | N | Mean(SD) | Fixed, 95% CI | | Fixed, 95% CI |
| Changrani 2008 | 42 | 16.6 (11.2) | 20 | 18.8 (10.4) | | 49.19% | -0.2[-0.73,0.34] |
| Winzelberg 2003 | 28 | 11.1 (7.4) | 30 | 16.1 (10.4) | | 50.81% | -0.54[-1.07,-0.02] |
| **Total ***** | **70** | | **50** | | | **100%** | **-0.37[-0.75,0]** |
| Heterogeneity: Tau²=0; Chi²=0.82, df=1(P=0.37); I²=0% | | | | | | | |
| Test for overall effect: Z=1.96(P=0.05) | | | | | | | |



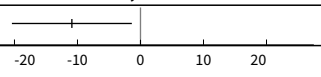

### Analysis 1.3. Comparison 1 Online support group versus usual care, Outcome 3 Quality of life post intervention.

| Study or subgroup | Online support | | Control | | Std. Mean Difference | Weight | Std. Mean Difference |
|---|---|---|---|---|---|---|---|
| | N | Mean(SD) | N | Mean(SD) | Fixed, 95% CI | | Fixed, 95% CI |
| Changrani 2008 | 42 | 68.7 (17.1) | 20 | 62.5 (17.7) | | 43.71% | 0.35[-0.18,0.89] |
| Salzer 2010 | 51 | 101.6 (19.2) | 27 | 110.8 (19.2) | | 56.29% | -0.47[-0.95,-0] |
| **Total ***** | **93** | | **47** | | | **100%** | **-0.11[-0.47,0.24]** |
| Heterogeneity: Tau²=0; Chi²=5.14, df=1(P=0.02); I²=80.54% | | | | | | | |
| Test for overall effect: Z=0.62(P=0.54) | | | | | | | |



**Analysis 1.4. Comparison 1 Online support group versus usual care, Outcome 4 Quality of life 12 months post intervention.**

| Study or subgroup | Online support | | Control | | Mean Difference | Weight | Mean Difference |
|---|---|---|---|---|---|---|---|
| | N | Mean(SD) | N | Mean(SD) | Fixed, 95% CI | | Fixed, 95% CI |
| Salzer 2010 | 51 | 102.8 (20.4) | 27 | 113.7 (20.4) | | 0% | -10.89[-20.41,-1.37] |




## APPENDICES

### Appendix 1. CENTRAL

Search strategy for the Cochrane Central Register of Controlled Trials (CENTRAL) via the Cochrane Library:

#1 MeSH descriptor: [Breast Neoplasms] explode all trees
#2 breast near cancer*
#3 breast near neoplasm*
#4 breast near carcinoma*
#5 breast near tumour*
#6 breast near tumor*
#7 #1 or #2 or #3 or #4 or #5 or #6
#8 MeSH descriptor: [Self-Help Groups] explode all trees
#9 ((online or on-line or web or internet or web-based) and support group*)
#10 chatroom*
#11 chat room*
#12 bulletin board
#13 social network
#14 MeSH descriptor: [Social Support] explode all trees
#15 MeSH descriptor: [Electronic Mail] explode all trees
#16 email*
#17 #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16
#18 #7 and #17

### Appendix 2. MEDLINE

Search strategy for MEDLINE via OvidSP:

| | |
|---|---|
| 1 | randomized controlled trial.pt. |
| 2 | controlled clinical trial.pt. |
| 3 | randomized.ab. |
| 4 | placebo.ab. |
| 5 | Clinical Trials as Topic/ |
| 6 | randomly.ab. |
| 7 | trial.ti. |
| 8 | (crossover or cross-over).tw. |

*(Continued)*

| | |
|---|---|
| 9 | Pragmatic Clinical Trials as Topic/ |
| 10 | pragmatic clinical trial.pt. |
| 11 | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 |
| 12 | exp Breast Neoplasms/ |
| 13 | (breast adj6 cancer$).tw. |
| 14 | (breast adj6 neoplasm$).tw. |
| 15 | (breast adj6 carcinoma$).tw. |
| 16 | (breast adj6 tumour$).tw. |
| 17 | (breast adj6 tumor$).tw. |
| 18 | 12 or 13 or 14 or 15 or 16 or 17 |
| 19 | exp Self-Help Groups/ |
| 20 | support group*.tw. |
| 21 | ((online or on-line or web or internet or web-based) and support group*).tw. |
| 22 | chatroom*.tw. |
| 23 | chat room*.tw. |
| 24 | bulletin board.tw. |
| 25 | social network.tw. |
| 26 | exp Social Support/ |
| 27 | exp Electronic Mail/ |
| 28 | email*.tw. |
| 29 | 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 |
| 30 | 11 and 18 and 29 |
| 31 | Animals/ not Humans/ |
| 32 | 30 not 31 |

## Appendix 3. Embase

Search strategy for Embase via Embase.com used in 2015:

1. random* OR factorial* OR crossover* OR cross NEXT/1 over* OR placebo* OR (doubl* AND blind*) OR (singl* AND blind*) OR assign* OR allocat* OR volunteer* OR 'crossover procedure'/exp OR 'double blind procedure'/exp OR 'randomized controlled trial'/exp OR 'single blind procedure'/exp

2. 'breast'/exp OR 'breast disease'/exp AND 'neoplasm'/exp OR 'breast tumor'/exp OR (breast* NEAR/5 neoplas*):ab,ti OR (breast* NEAR/5 cancer*):ab,ti OR (breast* NEAR/5 carcin*):ab,ti OR (breast* NEAR/5 tumo*):ab,ti OR (breast* NEAR/5 metasta*):ab,ti OR (breast* NEAR/5 malig*):ab,ti
3. 'self help'/exp OR 'self help'
4. 'support group'/exp OR 'support group'
5. online OR 'on line' OR web OR 'internet'/exp OR internet OR 'web-based' AND ('support group'/exp OR 'support group')
6. chatroom*
7. 'chat room'
8. 'bulletin board'
9. 'social network'/exp OR 'social network'
10. 'social support'/exp OR 'social support'
11. 'e-mail'/exp OR 'e-mail'
12. #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11
13. #1 AND #2 AND #12
14. #13 NOT ([animals]/lim NOT [humans]/lim)
15. #14 AND [embase]/lim

Search strategy for Embase via OvidSP used from 2016:

| | |
|---|---|
| 1 | Randomized controlled trial/ |
| 2 | Controlled clinical study/ |
| 3 | Random$.ti,ab. |
| 4 | randomization/ |
| 5 | intermethod comparison/ |
| 6 | placebo.ti,ab. |
| 7 | (compare or compared or comparison).ti. |
| 8 | ((evaluated or evaluate or evaluating or assessed or assess) and (compare or compared or comparing or comparison)).ab. |
| 9 | (open adj label).ti,ab. |
| 10 | ((double or single or doubly or singly) adj (blind or blinded or blindly)).ti,ab. |
| 11 | double blind procedure/ |
| 12 | parallel group$1.ti,ab. |
| 13 | (crossover or cross over).ti,ab. |
| 14 | ((assign$ or match or matched or allocation) adj5 (alternate or group$1 or intervention$1 or patient$1 or subject$1 or participant$1)).ti,ab. |
| 15 | (assigned or allocated).ti,ab. |
| 16 | (controlled adj7 (study or design or trial)).ti,ab. |
| 17 | (volunteer or volunteers).ti,ab. |

*(Continued)*

| | |
|---|---|
| 18 | human experiment/ |
| 19 | trial.ti. |
| 20 | or/1-19 |
| 21 | exp breast/ |
| 22 | exp breast disease/ |
| 23 | (21 or 22) and exp neoplasm/ |
| 24 | exp breast tumor/ |
| 25 | exp breast cancer/ |
| 26 | exp breast carcinoma/ |
| 27 | (breast$ adj5 (neoplas$ or cancer$ or carcin$ or tumo$ or metasta$ or malig$)).ti,ab. |
| 28 | or/21-27 |
| 29 | exp self help/ |
| 30 | self help.tw. |
| 31 | exp support group/ |
| 32 | support group.tw. |
| 33 | ((online or on line or web or internet or web-based).tw. or exp internet/) and (exp support group/ or support group.tw.) |
| 34 | chatroom*.tw. |
| 35 | chat room.tw. |
| 36 | bulletin board.tw. |
| 37 | exp social network/ |
| 38 | social network.tw. |
| 39 | exp social support/ |
| 40 | social support.tw. |
| 41 | exp e-mail/ |
| 42 | e-mail.tw. |
| 43 | or/29-42 |
| 44 | 20 and 28 and 43 |

## Appendix 4. PsycINFO

Search strategy for PsycINFO via OvidSP:

| | |
|---|---|
| 1 | exp Treatment Effectiveness Evaluation/ |
| 2 | exp Treatment Outcomes/ |
| 3 | exp Placebo/ |
| 4 | exp Followup Studies/ |
| 5 | placebo*.tw. |
| 6 | random*.tw. |
| 7 | comparative stud*.tw. |
| 8 | (clinical adj3 trial*).tw. |
| 9 | (research adj3 design).tw. |
| 10 | (evaluat* adj3 stud*).tw. |
| 11 | (clinical adj3 trial*).tw. |
| 12 | (research adj3 design).tw. |
| 13 | (evaluat* adj3 stud*).tw. |
| 14 | (prospectiv* adj3 stud*).tw. |
| 15 | ((singl* or doubl* or trebl* or tripl*) adj3 (blind* or mask*)).tw. |
| 16 | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 |
| 17 | exp Breast Neoplasms/ |
| 18 | (breast adj6 cancer$).tw. |
| 19 | (breast adj6 neoplasm$).tw. |
| 20 | (breast adj6 carcinoma$).tw. |
| 21 | (breast adj6 tumour$).tw. |
| 22 | (breast adj6 tumor$).tw. |
| 23 | 17 or 18 or 19 or 20 or 21 or 22 |
| 24 | exp Support Groups/ or exp Social Support/ |
| 25 | support group*.tw. |
| 26 | ((online or on-line or web or internet or web-based) and support group*).tw. |

(Continued)

| | |
|---|---|
| 27 | chatroom*.tw. |
| 28 | chat room*.tw. |
| 29 | bulletin board.tw. |
| 30 | social network.tw. |
| 31 | exp Computer Mediated Communication/ |
| 32 | email*.tw. |
| 33 | 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 |
| 34 | 16 and 23 and 33 |

## Appendix 5. WHO ICTRP

**Basic searches:**

1. Online support groups for women with breast cancer

2. Breast cancer AND support group

3. Breast cancer AND online support group

4. Breast cancer AND on-line support group

5. Breast cancer AND internet support group

**Advanced searches:**

1. Title: online support groups for women with breast cancer

Recruitment status: all

2. Condition: breast cancer OR breast neoplasm

Intervention: online support group* OR on-line support group* OR internet support group* OR social network OR email OR bulletin board OR chat room

Recruitment status: all

3. Condition: breast cancer OR breast neoplasm

Intervention: Internet support group* OR web support group* OR bulletin board

Recruitment status: all

## Appendix 6. ClinicalTrials.gov

**Basic searches:**

1. Online support groups for women with breast cancer

2. Breast cancer AND support group*

3. Breast cancer AND online support group*

4. Breast cancer AND on-line support group*

5. Breast cancer AND internet support group*

**Advanced searches:**

1. Title: online support groups for women with breast cancer

Recruitment: all studies

Study results: all studies

Study type: all studies

Gender: all studies

2. Condition: breast cancer

Intervention: online support group* OR on-line support group* OR internet support group* OR social network OR email OR bulletin board OR chat room OR electronic mail

Recruitment: all studies

Study results: all studies

Study type: all studies

Gender: all studies

3. Condition: breast cancer

Intervention: Internet support group* OR web support group* OR bulletin board

Recruitment: all studies

Study results: all studies

Study type: all studies

Gender: all studies

## CONTRIBUTIONS OF AUTHORS

Drafting the protocol: EM.
Selecting studies: EM, KP.
Extracting data from studies: EM, KP.
Entering data into Review Manager 5 (RevMan 2014): EM, KP.
Carrying out the analysis: EM, KP, IB.
Interpreting the analysis: EM, KP, IH, LN, IB.
Drafting the final review: EM.
Resolving disagreements: LN, IH.
Updating the review: EM.

## DECLARATIONS OF INTEREST

EM: nothing to declare.
KP: nothing to declare.
IH: nothing to declare.
LN: nothing to declare.
IB: nothing to declare

## SOURCES OF SUPPORT

### Internal sources

- Ulster University, Other.

### External sources

- HSC R&D Division of the Public Health Agency (Northern Ireland) has funded Eilis McCaughan to undertake this review as part of its training scheme, UK.

  Salary

## DIFFERENCES BETWEEN PROTOCOL AND REVIEW

None of the included studies measured 'emotional outcome'. One study (Salzer 2010) measured what investigators termed 'psychological distress' (in the abstract). Terms used in the text were 'distress' and 'cancer-specific distress'. It seems that Salzer 2010 used these terms interchangeably. The protocol described the POMS (used in Salzer 2010 to measure distress) as a tool used to measure 'emotional distress'. Although data for analysis were missing, it seems appropriate to mention that Salzer 2010 reported no positive effects of intervention on distress.

## INDEX TERMS

### Medical Subject Headings (MeSH)

Anxiety [therapy]; Breast Neoplasms [*psychology]; Consumer Health Information [*statistics & numerical data]; Depression [therapy]; Peer Group; Quality of Life; Randomized Controlled Trials as Topic; Self-Help Groups [*statistics & numerical data]; Time Factors

### MeSH check words

Female; Humans